

# Lived Experience Panel Summary

**2023 National Research Summit on Care, Services, and Supports for Persons with  
Dementia and Their Care Partners/Caregivers**

**National Institute on Aging**

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This meeting summary was prepared by Rose Li and Associates (RLA), under contract to the National Institute on Aging (NIA). The opinions, thoughts, and themes expressed in this document reflect both individual and collective opinions of the Lived Experience Panel members and not necessarily those of NIA. Contributions to the panel recruitment and facilitation and to the meeting summary by the following individuals are gratefully acknowledged: Amy Kiefer, Dana Carluccio, Gary Epstein-Lubow, Chandra Keller, Jessica Boten, Kerry Lanigan, Monica Moreno, and Nancy Tuvevsson.

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## Panel Overview

As part of the 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers (“The Summit”), the National Institute on Aging (NIA) convened a Lived Experience Panel to solicit feedback from individuals living with dementia and care partners/caregivers of persons living with dementia (PLWD). PLWD refers to persons living with cognitive symptoms including mild cognitive impairment or diagnosed dementia. The purpose of the Lived Experience Panel was to further one of the key goals of The Summit: To identify remaining unmet research needs with input from the research community, PLWD, and their care partners, those who provide healthcare or services and supports to persons living with dementia, and other stakeholders.

## Feedback Summary

### **Living Well with Dementia and What Matters Most to Persons Living with Dementia and Their Care Partners/Caregivers**

Panelists living with dementia emphasized the importance of staying socially engaged, spending time with family, and remaining as independent as possible. Panelists shared that technological devices such as smartphone apps, smart watches, audiobooks, and home devices like Alexa are helping them maintain some degree of independence. Others shared their enjoyment of creative projects and hobbies, including caring for pets, learning Spanish, practicing piano, and home decorating. One panelist was “trying to... learn how to dance again, to be able to dance with [their] granddaughter.” Several panelists described finding meaning in advocacy work and educating others about dementia.

Many panelists living with dementia expressed the desire to remain at home as long as possible. Some noted the importance of not living alone and having the comfort of family members’ presence. Panelists who are current or former caregivers of persons living with dementia likewise emphasized the importance of both them and the person living with dementia staying socially engaged. They reported struggling to maintain the right balance between safety and independence for their loved ones living with dementia. Safety was a preeminent concern for several caregivers, who worried about fall hazards and leaving their loved ones unattended but struggled not to appear overbearing or as if they were hovering.

Caregivers expressed the need for breaks and for having their own circle of social support, but they also shared the importance of being there for their loved ones, even as the disease progressed: “Living well is still staying connected to my [loved one] and making sure that my kids, now that they're older and they understand more, spend time with her.”

“To be with her not just in the words I say, but in my entire body, language, and in terms of her communicating with me, she does the same thing, not just with an incandescent 150-Watt smile, but just the way she holds her body. And she doesn't have complete control of it anymore, but I can tell when she is really happy to see me, even though she doesn't know who I

am. She just knows that whoever the heck I am, I'm a nice guy, and that's sufficient for me."

### **Key Themes**

- People living with cognitive symptoms expressed the desire to maintain their independence and discussed the potential use of technology to enhance independence.
- Family caregivers emphasized the need to stay socially engaged and active while also addressing safety.
- Family caregivers shared the need to balance personal breaks with maintaining safety and connection to their loved ones.

### **Challenges and Barriers to Living Well and Meeting Personal Goals**

Panelists with dementia, mild cognitive impairment, or other cognitive symptoms expressed frustration with forgetting daily tasks, events, and locations, and with the need for family members to provide constant reminders. They experienced profound sadness about forgetting important social obligations, such as birthdays and funerals.

They also reported distress at losing their ability to find the right words and being slower at processing information, and in noticing others' reactions and perceived discomfort regarding their cognitive challenges. Other people's lack of knowledge about mild cognitive impairment (MCI) and dementia and inappropriate responses are a source of frustration and distress. Panelists living with dementia shared that people sometimes talk to them as if they were children or were otherwise disrespectful. They spoke of feeling frustrated when people attempt to comfort them by minimizing their symptoms by saying that they forget things, too, without acknowledging the difference between normal age-related memory loss and living with a cognitive impairment.

Panelists living with dementia, mild cognitive impairment, or other cognitive symptoms also expressed frustration at not being able to drive, and how it prevented them from being able to remain independent and participate in activities and social engagements. Several panelists living with dementia reported feeling a sense of loss from not being able to work or maintain work-based social connections. As one panelist described, "Not being able to work anymore has been so frustrating for me. I loved what I did. I was in my career [for] over thirty years, and I'm glad I don't [have to work], in a sense, because it was an extremely visible, stressful position. But on the flip side I lost a lot of who I was at the time." A panelist who needed to retire earlier than planned experienced several financial challenges.

Caregiver panelists reported frustration with seeing their loved ones' confusion and feeling helpless to alleviate that confusion. Some noted frustration with a lack of family support around caregiving, or with family members interfering with their caregiving decisions despite not being the primary care provider. Many felt staying engaged in activities and hobbies they enjoyed was extremely difficult or impossible given their current caregiving responsibilities. Sometimes friends failed to understand their caregiving responsibilities or what they were going through,

and caregivers' friend circles shifted or diminished shrank as a result. Their remaining friendships, however, were highly valued. Caregivers also struggled with not being recognized by their loved ones as the disease progressed, and keeping perspective that their loved ones' sometimes hurtful statements and dementia-related behaviors were the result of the disease and should not be taken personally. Despite trying to maintain healthy lifestyles, caregivers reported immense, constant stress related to caregiving.

### ***Key Themes***

- The loss of social relationships and the ability to engage in hobbies and other activities is distressing to persons living with cognitive symptoms and their caregivers.
- Dealing with others' misperceptions about cognitive symptoms and being treated with condescension and paternalism were deeply upsetting to people living with cognitive symptoms.
- Dealing with a loved one's dementia-related behaviors and memory loss were particularly challenging for caregivers.

### **Approaches to Overcoming Barriers to Living Well with Dementia**

Several panelists living with dementia, mild cognitive impairment, or other cognitive symptoms noted the need for more support groups and for greater ability to connect with others at similar disease stages who understand what they are going through. One panelist shared that a spouse had to take time off work to drive two hours for the panelist to attend a monthly support group, where the panelist could talk openly about the disease ("It's embarrassing. It's humiliating. It's scary as hell") without burdening the spouse or friends. Another expressed frustration at not being able to identify and reach out to local individuals with MCI or dementia in order to connect with them. Another caregiver noted that finding support groups where they feel comfortable and represented is important.

Several caregivers shared a desire for more general awareness of the burden of caregiving and the need for more systemic support for caregivers. One caregiver expressed the need for "a broader recognition and understanding of how the disease affects families, employees, and especially primary caregivers." This caregiver added that, "Paid family and medical leave might signal the importance of caregiving in general and primary caregivers specifically." Another expressed the need for additional support groups and adult day programs specifically for people with memory loss, to help them and their loved ones avoid isolation and to provide caregivers with much needed relief.

### ***Key Themes***

- People living with cognitive symptoms expressed the need for more accessible forms of support, particularly for support groups where they could connect with others experiencing cognitive symptoms.
- Caregivers emphasized the need for more functional and formal support, including adult daycare centers and policies that acknowledge and address the importance and strain of

caregiving, such as paid family and medical leave.

### **Care-Related Experiences and Preferences Related to Screening and Diagnosis**

Panelists with dementia, mild cognitive impairment, or other cognitive symptoms expressed the need for comprehensive, easy-to-access care, including psychological counseling and cognitive and speech therapy. They want a one-stop-shop where they can receive all dementia-related care, similar to what is available at some heart disease and diabetes clinics. Some had a good experience receiving guidance on next steps and referrals following their diagnosis. One panelist described receiving immediate referrals for counseling and cognitive and speech therapies. Others, however, stated they were not given a plan on what to expect or how to plan for future care and financial needs. Panelists agreed that everyone receiving a diagnosis of MCI, Alzheimer's or other dementia should receive a roadmap outlining resources and next steps. The absence of this information made navigating the health care system more challenging and distressing for persons living with dementia and their care partners. It was also perceived as stigmatizing. As one caregiver noted, "The all-too-common diagnostic drop and dash out the door is not only horrid in itself, but it also reinforces the stigma. 'If the doctor can't even bear to talk about the situation, how awful it must be.'"

One caregiver shared having to seek out a geriatrician to receive dementia-specific care (e.g., medication adjustments to reduce the risk of falls) and education about dementia-related behaviors, because a loved one's primary care physician had attributed cognitive and behavioral changes to old age.

### **Key Themes**

- People living with cognitive symptoms were often not provided with adequate guidance, referrals, or support following diagnosis. In addition to the lost opportunity for providing follow-up care, a lack of guidance was sometimes seen as commentary on the devastating nature of the disease and was extremely distressing.
- Caregivers reported that prior to their loved ones' diagnoses, their concerns about their cognitive and behavioral symptoms were sometimes dismissed by health care providers.

### **Concerns Regarding Disease Progression**

Panelists living with dementia, mild cognitive impairment, or other cognitive symptoms expressed concern regarding the loss of independence and function, specifically, their ability to drive and to perform the basic activities of daily living, noting changes in balance and tremors as particularly worrisome.

Panelists discussed several barriers to care access, particularly related to costs and the logistical challenges of obtaining care as the disease progresses. They noted that receiving appropriate care is especially challenging for low-income people and for those who have not received a diagnosis, who may not be fully cognizant of their need for services and support. Caregivers reported challenges in getting their loved ones deemed eligible for certain healthcare benefits.

One caregiver experienced tremendous difficulty obtaining dementia-friendly medical care for a parent with advanced disease. A doctor wanted an early morning visit, but the parent had difficulty getting up and dressed for early morning appointments. Once an afternoon visit was finally scheduled, the parent had to wait to see the doctor for forty-five minutes. “And I told them, when you have a patient who has a diagnosis [of dementia], especially in more advanced stages, ten minutes at the most...They don't understand that, so by the time the doctor came in [the parent] had ripped up the paper on a chair... and was frustrated, aggravated, because [my parent] doesn't understand [having] to sit down and wait.” A panelist living with dementia echoed these concerns, stating that patients living with dementia should be flagged prior to arriving at the doctor’s office to allow the staff to expedite their visit with the doctor upon arrival.

Caregivers reported challenges extending home-based care assistance for their loved ones during necessary work and travel. Some caregivers expressed their desire to avoid nursing home care for their loved ones, which they regarded as generally poor. A caregiver whose spouse had been moved into a nursing home reported that the spouse was receiving excellent care overall, but the care workers did not seem to be able to detect when the person was uncomfortable or in pain. Another noted the need to create some emotional distance from a parent as the disease progressed, by maintaining outside interests and other social connections. This panelist also reported that a support group of peers had helped “meet [my parent] where they were at,” as opposed to trying to remind the parent of a former self. The caregiver panelist functioned best by trying to strengthen what connection and abilities remained rather than focusing on the losses experienced by the person living with dementia.

### ***Key Themes***

- The process of obtaining care is challenging, especially because people living with cognitive symptoms are unable to drive.
- Caregivers emphasized the need for more dementia-friendly care, including later in the day appointments, reduced wait times, and training and notifications for all clinical staff.

### **Considerations Related to Advanced Stage Disease and End of Life Care**

One panelist reported frustration that some states provide financial support for nursing home care but not for home-based care. He noted that a friend caring for a loved one living with Alzheimer’s disease was forced to place that individual in a nursing home simply because the friend could not afford incontinence briefs.

A panelist living with cognitive symptoms shared the desire to avoid burdening adult children with complex end-of-life care decisions. Participating in a research study had prompted the panelist to consider personal end-of-life preferences and to finalize all the complex paperwork involved in planning future care.

A caregiver shared tremendous gratitude for the excellent hospice care a loved one received at the end of life, including having a nurse visit and aides who came to bathe her at home. A panelist living with dementia hoped to receive hospice care at home.

Not all experiences with hospice and palliative care were positive. One caregiver shared a negative experience with hospice care in a long-term care community: “The facility went from talking to me about palliative care to not telling me when they had actually transitioned [my mother] to hospice.” The caregiver had wanted the loved one to receive hospice care at a previously chosen and familiar long-term care community but had not contacted them early enough to ensure the loved one could receive care there. Another caregiver reported dissatisfaction with care workers who provided hospice for a loved one and shared having to change organizations several times to find care that the panelist and loved one were comfortable with.

### ***Key Themes***

- People living with cognitive symptoms and caregivers expressed the desire for more home-based support, particularly financial support, and noted that financial constraints can sometimes push individuals into long-term care.
- Panelists living with cognitive symptoms and with a family history of dementia expressed the desire to avoid burdening their children and partners with later stage care.
- Caregivers shared a variety of experiences with hospice care and emphasized the need for clear communication and planning for end-of-life care.

### **Participation in Research**

One caregiver mentioned knowing several caregivers who were reluctant to participate in research because they did not want to be someone else’s project. Given a strong family history of Alzheimer’s, this caregiver was now considering participating in research that may benefit other relatives but had been wary of learning more about their risk of developing Alzheimer’s as potentially distressing. A panelist living with dementia noted that participating in research was too logistically challenging because the nearest research sites were several hours’ drive from their home. This panelist shared the view that researchers should provide financial compensation for travel, gas, lodging, and for family members’ time if they want to improve participation in research.

One caregiver described receiving social support, structure, and disease education from having a loved one participate in research shortly after diagnosis. Another caregiver had participated in a study on caregiver burnout, which was an important way for the caregiver to share experiences and warn others to take care of themselves and find their own sources of support. A panelist living with dementia participated in research to try to help others including their children and grandchildren. The panelist noted, however, that their care partner had to take a full day off work each month to transport them to study visits.



***Key Themes***

- Several panelists shared positive experiences participating in research and expressed the desire to help others through their participation.
- Panelists also reported that travel-related and financial hurdles frequently constrained their ability to participate.

## **About the Lived Experience Panel**

The Lived Experience Panel consisted of four persons living with cognitive symptoms or diagnosed dementia (PLWD) and five care partners/caregivers. Monica Moreno and Kerry Lanigan of the Alzheimer’s Association® identified and recruited the panel members. The recruitment aimed to identify a geographically, racially, and experientially (in terms of disease type and age of onset) diverse panel. Six panel members were female, and three were male. Five panel members were White/Caucasian, two were Black/African American, one was Hispanic, and one was Filipino. Panelists lived through the contiguous United States in rural and urban areas.

Panelists participated in two 90-minute Lived Experience Panel virtual feedback sessions. The first session was held in December 2022 and the second was held in January 2023. Dr. Gary Epstein-Lubow and Monica Moreno facilitated both feedback sessions.

## **Panel Members**

### *Facilitators*

Gary Epstein-Lubow, MD, Associate Professor of Psychiatry and Human Behavior, Associate Professor of Medical Science, Alpert Medical School of Brown University; Associate Professor of Health Services, Policy and Practice, Brown University School of Public Health; Team Leader, Stakeholder Engagement Team, NIA IMPACT Collaboratory  
Monica Moreno, Senior Director, Care and Support, Alzheimer's Association

### *Panelists*

Dave Arnold  
Willetha Barnette  
Dr. Leslie Burger  
Roberta Cruz  
LuPita Gutierrez-Parker  
Reda Harrison  
Priscilla Jean-Louis  
Deborah Jobe  
Jim Mangi